A Qualitative Meta-synthesis: Family Involvement in Decision Making for People with Dementia in Residential Aged Care

Abstract

Aim. Involving people in decisions about their care is good practice and ensures optimal outcomes. Despite considerable research, in practice family involvement in decision making can be challenging for both care staff and families. The aim of this review was to identify and appraise existing knowledge about family involvement in decision making for people with dementia living in residential aged care.

Methods. This Joanna Briggs Institute meta-synthesis considered studies that investigate involvement of family members in decision making for people with dementia in residential aged care settings. While quantitative and qualitative studies were included in the review, this paper presents the qualitative findings. A comprehensive search of studies was conducted in 15 electronic databases. The search was limited to papers published in English, from 1990 – 2013. Twenty six studies were identified as relevant for this review; 16 were qualitative papers reporting on 15 studies. Two independent reviewers assessed the studies for methodological validity and extracted the data using the Joanna Briggs Institute standardised Qualitative Assessment and Review Instrument (JBI-QARI). The findings were synthesised using JBI-QARI.

Results. The findings related to the decisions encountered and made by family surrogates, family perceptions of and preferences for their role/s, factors regarding treatment decisions and the collaborative decision making process, and outcomes for family decision makers.

Conclusion. Results indicate varied and complex experiences and multiple factors influencing decision making. Communication and contacts between staff and families and the support available for families should be addressed, as well as the role of different stakeholders in decisions.

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Keywords: dementia; family; decision making; residential aged care; qualitative; systematic review; nursing

Background

Involving older people in decisions about their care is universally recognised as good practice, and important in ensuring optimal outcomes. Particularly in nursing literature, focus has been placed on the care recipient's role in care planning and decision making in residential, hospital, or community settings[1, 2]. This discussion has been extended to people with dementia, centring on notions of personhood, citizenship, and the importance of autonomy and choice[3, 4, 5].

Dementia describes a group of disorders affecting the brain that cause symptoms relating to language, perception, cognitive skills, and memory[6]. As the condition progresses the ability of the person with dementia to participate fully in care decisions declines. Indeed, in the context of residential care where the cognitive and other impairment caused by dementia is often significant and care needs are high, it is often the case that the decision making capacity of the person with dementia will be limited. At the same time, their care needs progressively change, creating an imperative for ongoing decision making[7]. In these cases surrogates or proxies, often family members, are considered well placed to work alongside care staff and the person with dementia to ensure their wishes are followed in decision making[8]. Thus, the ongoing deterioration of the person with dementia's condition makes collaborative decision making by family surrogates with health professionals increasingly important.

It must be noted, of course, that a diagnosis of dementia does not automatically mean an individual cannot actively participate in decision making. As such, the focus of this review on family involvement in decision making does not preclude involvement of the person with dementia, and nor does it assume that family involvement in decision making is necessarily the most appropriate course. Rather, the review aims to scope the existing knowledge about family involvement in decision making for people with dementia living in aged care facilities in order to

inform practice in cases in which family proxies are required or preferred by the person with dementia.

The decisions in which family surrogates are involved are diverse, ranging from lifestyle choices[9], to medical decisions[10], to specific stages such as end-of-life (EOL) care[11]. Numerous factors contribute to the complex nature of surrogate decision making; these include who makes the decisions, how this authority is delegated, and what sources of information are available to guide decision making[12, 13]. For example, there is some debate regarding family members' ability to correctly identify care recipients' wishes[14, 15]. Further, families' experiences of decision making vary[16, 17]. For example, Dijkstra reported that families actively participated in care planning, but not all felt they had enough influence over the outcome, reporting concerns about the implementation of plans[15].

The ways residential aged care providers engage with family members and enable their participation have important implications for care provision. Despite research attention to this issue, in practice family involvement in decision making can be challenging for staff and families. It is therefore important to build the knowledge base to continue to improve outcomes for people with dementia and their families.

Aims

The objective of this systematic review was to appraise existing knowledge about family involvement in decision making for people with dementia living in residential aged care. While the complete review included qualitative and quantitative studies[17], this paper reports the qualitative component. The review questions were:

• Who are the decision makers for people with dementia living in residential care?

• What is the experience of decision making for family members in the residential care setting?

• What are the barriers or facilitators to decision making by families?

• What is the impact of decision making processes on family members?

• What is the impact of collaborative decision making with family on the person with dementia?

• What processes or strategies do family decision-makers use in decision making?

Search strategy

The review followed the Joanna Briggs Institute guidelines. This involved searching for papers meeting the inclusion criteria, assessing methodological quality and synthesising findings using the JBI Qualitative Assessment and Review Instrument (JBI-QARI). The literature search strategy is detailed in Table 1. The review included studies regarding people with dementia living in residential aged care, their families, and care staff. "Dementia" was not restricted to any specific diagnosis, stage, or severity[1]. There was no participant age limit. Care staff included any staff providing care to people with dementia in residential aged care. This included any paid providers of medical or care services who might be involved in decision making with or on behalf of people with dementia in residential care; for this reason, staff included nurses, personal carers and Assistants in Nursing (AINs), therapies staff, allied health staff, and physicians. Only studies including at least 70% participants with dementia in residential care (nursing home) settings were included. Other sites of care including assisted living were excluded, because these more community-based arrangements differ significantly across national contexts, and because they often do not involve an on-site staffing model which characterises residential aged care (nursing homes). Decision making included the physical, psychosocial, spiritual, and emotional domains of care but excluded decisions about entering residential care or financial issues. The

[1] Although it has been noted that the progress of dementia can impact on decision making in different ways, examination of the literature suggested that the restriction of the review to papers that included only a sample defined by their stage of dementia or functional status or other measure would result in a severe limitation in the findings.

search was limited to studies published in English during or after 1990[2].

Search outcome

Initially, excluding duplicates, 1029 qualitative and quantitative studies were identified. Following title and abstract review, 153 full text papers were retrieved and reviewed by two independent reviewers against the inclusion criteria. Twenty six papers were included in the full mixed method review (Figure 1). This paper reports the findings of the 16 qualitative papers (including one mixed methods study), outlined in Table 2. Separation of the qualitative and quantitative components of the review was necessary to provide the fullest possible explanation of the data within the confines of a journal paper; however, it must be acknowledged that this paper, and the quantitative findings paper also in this journal (ref TBC) each provide a partial picture in explaining family involvement in decision making for people with dementia who are living in residential care.

Methods of the review

The 16 papers were assessed by two reviewers for methodological rigour using the standardised JBI-QARI critical appraisal instrument (Figure 2). These studies all met the five key quality criteria identified by the reviewers (Figure 2) and none were excluded. It was noted, however, that the underlying philosophical position, the researchers' theoretical position, and their influence as researchers on the research were often not identified. Further, the degree to which participants' voices were represented and the ways papers were structured to connect quotations with analysis varied.

[2] Examination of the literature revealed limited relevant articles prior to 1990, with the volume of articles increasing during the 1990s to the present. While some seminal work regarding the role of family carers was published prior to 1990, examination of the literature suggested that it did not contribute significantly to the specific research questions addressed in this review.

Data extraction and synthesis

Data including samples, study methods, and findings relevant to the review questions were extracted from the papers using JBI-QARI. Each finding was a theme or subtheme as reported in a paper, supported by data such as participant quotes. Findings were rated according to JBI-QARI levels of credibility (Table 3). Findings were categorised based on similarity in meaning using JBI-QARI, and subjected to meta-synthesis to produce a single set of aggregated findings. Categorisation and synthesis was cross-checked by two reviewers.

Results

Study designs and methods are detailed in Table 2. Designs included phenomenology, grounded theory, ethnography, or specified only as "qualitative". Thirteen papers reported findings of individual interviews or focus groups, two used observation, and one mixed method study used interviews with a questionnaire. Data were commonly analysed using thematic analysis. Participants included family members, physicians and other care staff including nurses. Over half the studies focused on treatment or EOL care decisions.

A total of 79 findings were extracted from the 16 papers. Twenty seven findings were considered "credible" and 52 "unequivocal" according to the JBI levels of credibility. The findings were grouped into 14 categories which were clustered into four synthesised findings.

Synthesis 1: Family caregiver roles vary

A total of 12 findings formed three categories which were grouped into the first synthesised finding. This finding reflected family perceptions of, and preferences for, their role (Figure 3).

1.1 Acquisition of decision making role

One study reflected the different ways in which families acquire their role. In their study

with 39 family members, Elliott et al.[11] found that surrogates acquired decision making authority differently: in most cases, they assumed the role when a decision was unavoidable; others were explicitly designated as surrogates in advance; and some appointed themselves, but this was associated with decision making conflict.

1.2 Advocate role

Three papers described the family's role as advocate. This related to promoting "comfort" (e.g., lifestyle choices) and "protection" (e.g., from life-sustaining treatments)[11]. For daughters in Legault and Ducharme's[18] study, the role involved ongoing evaluation of the quality of care, weighting this against contextual constraints, and taking action in response (e.g. hiring a private attendant). Siegrist[19] described this spokesperson role and making sure their relative was cared for properly as part of "making time" for their relative.

1.3 Family perceptions and preferences for the extent of their role

Three findings suggested that family perceptions and preferences for their role vary. In Caron et al.'s[20] study, family were unclear about their role and what was expected; none had clear guidance and meetings with staff were inconsistent. Family caregivers' approaches varied from taking total control over decision making to delegating control to medical staff. Participating in decision making was more desirable for some caregivers than others, whereas some would have liked to be more involved. Similarly, Hertzberg and Ekman[21] found family members wanted to be involved but could not always communicate this. It was important for family to have their views and their accounts of their relative taken seriously and therefore influence care. Conversely, The et al.[22] found that family was involved from admission through regular meetings.

Thus, the role families take in decision making and how they acquire it, their degree of

involvement, and how they perceive this role can vary. This appears to be associated with their opportunities for involvement and can lead to quite different courses of action in their decision making.

Synthesis 2: Importance of communication and relationships with care provider staff

A total of 32 findings formed four categories, grouped into the second synthesised finding. This finding reflected the importance of information exchange, communication, and relationships between family and staff to the effectiveness of family decision making (Figure 4).

2.1 Relationships between staff and family, and extent of family involvement

Synthesis of 12 findings revealed that the relationship between staff and family and the extent to which staff discuss with and involve family varies. Hertzberg and Ekman[21] found that staff and families reported difficulties sharing and obtaining information from each other. In addition, staff tended not to communicate disagreement with families' perceptions or preferences, even when they found family involvement problematic. Relatives, in turn, felt they were being asked not to interfere in care provision and wanted greater follow-up from staff. Similarly, Caron et al.[23] reported limited and inconsistent contact and discussions with the care provider as a significant frustration for families. They found an inconsistent approach to meetings, with different degrees of contact reported by families. Nearly all families in their study reported wanting more frequent meetings with the care team, and some wanted planned, regular meetings even if not so frequent.

Nurse-family relationships were explored in more detail in two studies. Lopez et al.[24] found that registered and enrolled nurses in their sample perceived their role in "feeding decisions" as ambiguous and as focused on facilitating communication between the doctor and family, rather than advising. This reluctance to advise was increased by nurses' uncertainty about

their moral agency in feeding decisions, which they perceived to be "personal" and beyond their role, rather than a moral aspect of nursing care for which they had responsibility. In a study of negotiation processes between nurses and families, Ward-Griffin et al.[25] identified four types of family-nurse relationships: "conventional", with family as "visitor", entailing minimal negotiations; "competitive", involving conflict, mutually high expectations, interdependence, and attempts to control caregiving; "collaborative", involving high family participation, mutual decision making, negotiation, and consultation; and "carative", characterised by a strong emotional relationship, but positioning family as passive. These typologies have clear implications for family involvement, with each characterised by different degrees of family participation and authority in decision making processes.

Focusing on physicians, Helton et al.[26] found cultural differences in how the role of family in decision making was understood and operationalised. Dutch physicians reported more contact with, and knowledge of, the person with dementia and their family, which facilitated decision making. While valuing the family's contribution, Dutch physicians prioritised relieving suffering over what they saw as futile treatments, even if it contradicted the family's wishes. American physicians reported having little time to spend with the person with dementia and their family, more limited knowledge of the person, reliance on NH staff or emergency department physicians for information and a more deferential relationship with family.

2.2 Impact of information, communication and relationships

Seven findings suggested that good information, communication and relationships between staff and family help to facilitate shared decision making; poor communication and relationships, conversely, can negatively impact shared decision making. Caron et al.[23] identified personalised relationships with care providers as important for family to feel their views were

understood and listened to. While frequency and regularity of meetings varied, almost all caregivers wanted to meet with staff more often. They saw meetings as providing a better understanding of the illness, a chance to get answers, reassurance, and a feeling of involvement in care. Givens et al.[16] found that almost all families in their study were dissatisfied with physicians' inadequate communication, particularly about medical events, and that this hindered the family's advocacy role and decision making. Families reported having inadequate information to guide them, especially in deciding about an advance directive (AD) at admission, and suggested more education was needed regarding the disease and treatment, along with repeated discussion of ADs. Hertzberg and Ekman[21] further found that families questioned or criticised care indirectly to avoid negative consequences, which contributed to uncertainty in communication. Further, although staff reported trying not to reveal their disagreement with relatives' views and ideas, and avoiding confrontation, relatives sometimes reported feeling belittled by their responses. Both staff and families reported that staff only spontaneously shared essential information about major changes to care or treatment requiring permission or family involvement and that they should provide greater explanation prior to acting. Communication issues led to frustration, irritation, and uncertainty. Some families attributed making incorrect decisions to this lack of information.

2.3 Level of trust between staff and families

Three studies highlighted trust as important in family involvement in decision making. Caron et al.[23] reported that "blind trust", influenced by staff's professional status and knowledge, was associated with family feeling less need to participate in decisions and meant some caregivers delegated decisions to professionals. However, before delegating decisions, some caregivers built trust by interacting with staff. Legault and Ducharme[18] similarly found that level

of trust was important, but reported mixed findings. For some relatives, their trust in staff influenced their level of vigilance, whereas others supervised care despite trusting staff, while others again demonstrated blind trust, or felt that problems were minor and did not undermine their trust. Trust appeared to be dynamic and fluctuating. Hertzberg and Ekman[21] also identified some variation between families; some relatives deliberately made unannounced visits, whereas others preferred to give warning to avoid inconveniencing staff.

2.4 Factors affecting staff-family relationships and communication

Several studies emphasised the actions and attitudes of staff, staff-family interactions, and other contextual factors as important in the quality of relationships. For example, it was through interacting with staff that some caregivers built trust[23]. Trust was also facilitated by the care provider's personalised engagement with, and inclusive behaviour towards, the family as a care partner. First impressions and information received by family, staff responsiveness, and transparency after an incident were also important in the development and maintenance of trust[17].

Similarly, the four types of nurse-family relationships identified by Ward-Griffin et al.[25] appeared to be affected by the nurses' values. Those who did not seem to value relatives' views and expertise tended to have "conventional" or "competitive" relationships, whereas nurses adopting a family-centred approach tended to have "collaborative" or "carative" relationships with family. Further, positive relationships were supported by administrative and collegial support in the NH. With regard to relationships among staff, Hertzberg and Ekman[21] found strong ties between staff could make relatives feel excluded and high turnover made some relatives feel they could not continually invest in developing new relationships. Given the importance of staff-family relationships to collaborative decision making, the necessity to build new relationships as staffing profiles change is an important barrier to facilitating family

involvement decisions about care.

Families themselves used strategies to build relationships. Legault and Ducharme[18] found families developed reciprocal, collaborative relationships with staff and used a "diplomatic" communication style to maintain good relationships and their involvement. They used strategies (including allusions and indirect questions) to help maintain this relationship and avoid conflict with those on whom their relative was dependent.

The quality of staff-family relationships and communication thus varies, and depends on a range of interpersonal and contextual factors. It is vital that these factors are considered, as communication and relationships between staff and families impact on the capacity of family members to partner with staff in both the decision making process, and in responding to the decisions that are subsequently made.

Synthesis 3: Family surrogates base decision making on a range of factors including explicit and implicit wishes of their relative, other values, and the context of the illness

A total of 36 findings formed three categories, grouped into the third synthesised finding. This finding reflected the multiple factors influencing decision making (Figure 5).

3.1 Family decision makers' knowledge about the wishes of the person with dementia

Ten findings indicated that family decision makers have variable knowledge about the wishes of the person with dementia. Black et al.[12], for example, found surrogates' knowledge about their relative's wishes for EOL care ranged from very clear instructions, to nonspecific information, to no information at all. Family drew on several information sources regarding their relative's wishes. Their main source was advance directives (ADs); however, there was considerable variability in whether, when, and how these were prepared. Family also gained information through discussion with their relative, knowledge gathered over time through their

relative's expressed values, other decisions their relative had made, and other aspects of their life. Regardless of how the information was obtained, most surrogates confidently reported knowing their relative's wishes. Black et al. identified several barriers to the creation of ADs, including preferring to leave decisions to others and deference to others by the person with dementia. They reported various factors that led to discussions with the person about their preferences, including their desire to make sure these were known. However, discussions about wishes were affected by the person's level of dependence on their surrogate to act for them, the surrogate's desire to protect their relative from difficult discussions, and family trust and dynamics. Finally, exploring ADs for euthanasia in the Netherlands, de Boer et al.[27] found there was no ongoing discussion once the AD was drawn up, suggesting that even in cases where an AD exists, this may be all the communication that occurs.

3.2 Values, attitudes and beliefs of the family caregiver

The values, attitudes, and beliefs of the family are vital to decision making. Forbes et al.[28], for example, found that family values and goals guided decisions, although it was sometimes difficult for family to translate these into specific options. Surrogates made decisions that gave them peace after their relative's death. Caron et al.[23] further found shared values between family and medical staff facilitated decision making and helped reduce negative feelings. Differences in values did not change the decision, but families reported feeling less comfortable.

Values and beliefs about death and EOL care were particularly important. In de Boer et al.'s[27] study in the Netherlands, family were often reluctant to consider agreeing to the physician acting on an AD for euthanasia, or to foregoing treatment, despite their relative having an AD. Some did not feel ready to agree to euthanasia or felt the spouse of their relative would not have

agreed. However, relatives often declined life-prolonging treatment rather than acting on the AD for euthanasia. Some had little knowledge about the potential for euthanasia, whereas others had a clear opinion, even viewing it as a right. Forbes et al.[28] similarly found family caregivers had conflicting perceptions of, and beliefs about, death. Treatable conditions such as infections were not perceived as acceptable causes of death, nor were conditions that had not been declared terminal. Death was simultaneously accepted and forbidden, and both a tragedy and a blessing. Gessert et al.[29] further identified differences in attitudes and beliefs regarding EOL care between rural and urban family caregivers. For example, rural caregivers saw dying as natural, wished for death to be quick, preferred palliative options, and did not favour medical intervention. Urban caregivers ranged from accepting to actively resisting death, and from opposed to through to strongly favouring intervention. Most, however, favoured intervening to some degree, even if medical professionals disagreed. They supported more aggressive treatment and were less comfortable with withholding care.

Elliott et al.[11] found that family members gave variable weight to their own and their relative's interests. They used their relative's "wants", "needs" and "wishes" in three ways: surrogates mostly reported making decisions that balanced the interests of both parties; in other cases, they prioritised their relative's wishes; or, less commonly, the surrogate's interests took precedence.

3.3 Use of indicators of health, quality of life or illness

Twelve findings related to the use of indicators of health, quality of life, or illness to guide decisions. Caron et al.[20] found that quality of life was multidimensional and related to the stage of illness and overall health of the person with dementia. For these caregivers, dimensions of quality of life included communication and mobility, clinical issues, social participation, the

environment of the facility, quality of care, and knowledge of the individual's preferences and personality. The caregivers' assessment of quality of life informed their treatment decisions. Phases of EOL decision making were related to quality of life: the "transitory" phase, on admission, characterised by maintenance of quality of life and a high level of treatment; the "curative" phase, when an event required a change in treatment; the "uncertainty" phase, marked by doubts about, and difficulty in evaluating the relative's quality of life; and the "palliative" phase, when quality of life was completely diminished, focused on comfort and minimising suffering. Similarly, in de Boer et al.'s[27] study, some surrogates did not wish the physician to act on their relative's AD for euthanasia because they did not feel their relative was "suffering" (p. 993).

Forbes et al.[28] found that without clear understanding of the dying process, family wished to treat "treatable" problems, such as pneumonia, but did not wish to prolong dying through interventions such as ventilation. Surrogates assessed the short and long term consequences and benefits of decisions. The et al.[22] similarly found the illness process impacted on family decisions. Slow deterioration was seen as a natural part of the disease trajectory, with the decision to refrain from artificial administration of fluids and food seen as unproblematic. In cases of acute illness where the person with dementia was at the end stage of the disease or in a poor condition, doctors were reluctant to begin treatment; however, this did not necessarily mean family decided to withhold treatment. Decisions were generally made by the doctors, who were influenced by the condition of the person with dementia and the reaction of the family to the illness process and outcome.

Families can differ considerably in their approach to decision making, as multiple factors shape what, and how, decisions are made. Decision making is affected by the family's

understanding and knowledge of their relative's condition and its progression, concerns regarding quality of life, and other values and beliefs.

Synthesis 4: Decision making role poses a range of challenges as well as positive and negative consequences for surrogates

Seven findings formed four categories, grouped into the fourth synthesised finding. This finding reflected the challenges experienced by family decision makers, and positive and negative consequences of the decision making role (Figure 6).

4.1 Benefits for caregivers of participation in decision making

Participation in decision making has important implications for caregivers. Caron et al.[20] found most caregivers wanted to be involved – actively or passively – in decisions around care. Participation gave caregivers a sense of "contributing to the well being of their relative" (p. 125), gave them reassurance and better understanding of the disease, and helped them prepare for their relative's death.

4.2 Challenging and difficult decisions

Family caregivers face challenging and difficult decisions in their surrogate role. Givens et al.[16] particularly highlighted decisions such as the use of feeding tubes as a source of stress.

4.3 Absence of full understanding or information, or conflicting perceptions or preferences

Caregivers may also need to make decisions with inadequate information, or incomplete or conflicting understandings of illness and death. Caregivers face significant challenges in making decisions without an AD to guide them[30]. Forbes et al.[28] further identified that surrogates have difficulty conceptualising the dying trajectory or the conditions under which decisions may need to be made, such as "terminal" illness, "natural death" or "when the need arises".

4.4 Emotional impact on family

Two studies reported on how the decision making role impacted emotionally on caregivers. Forbes et al.[28], for example, reported that families experienced emotional burden and guilt in decision making and could find it difficult to discuss EOL decisions. Having an AD or knowing the values of the person with dementia did not necessarily alleviate this. Robinson[30] reported wives' experiences of being surrogates for their husbands; despite having ADs or knowing their husbands' wishes, some experienced difficulty, tension, and uncertainty in making decisions.

Thus the decision making role can be positive but also stressful, challenging, and emotionally strained. Family face difficult decisions, sometimes without adequate or clear information or ideas.

Discussion and application of findings

This review aimed to synthesise the evidence on family involvement in decision making for people with dementia living in residential aged care. The studies addressed different dimensions of the collaborative decision making process including communication dynamics between staff and family, who is involved in the decision making process, and factors that impact on family members' engagement in decision making. A number of key findings can be identified in relation to the review questions.

Two review questions addressed who the decision makers are for people with dementia in residential care, and what the experience is of family members acting as decision makers. The findings suggest that the roles of family caregivers – how the role is acquired, how they perceive it, experience it, and would prefer it to operate – vary. The extent to which decisions were discussed with surrogates was inconsistent both among and within studies; however, it is clear

that family members are not always involved in decision making processes that impact on care provision. Families had differing preferences regarding their involvement; several studies indicated that they preferred to be involved in decision making, and wanted information and time with staff to discuss care issues, so as to operationalise their involvement. Lack of time and opportunity for discussion with staff were key issues for surrogates, impacting upon their involvement. One strategy to improve engagement between staff and family members would be the early consultation between these groups (and the resident themselves where possible) through in-depth meetings upon resident's arrival to the residential care. Such meetings could ascertain the family member's knowledge of dementia and their communication preferences, resulting in more targeted responses. For example, identifying family member's knowledge could be followed by the organisation of education sessions to address identified knowledge deficits, and/or referral of the family members to counselling if they are unaware that their loved one has a terminal illness. In addition, the initial meeting could elicit family members' preferences for future meetings or participation in case conferences (e.g., timing, scheduling, frequency, length, etc.), and how information sharing between family and staff would best take place (e.g., discussion of family preferences, staff availability, who else should be involved in case conferences, etc.). Subsequent follow up meetings with family members may then review preferences or needs for communication and information-sharing, given that these can change over time. The intent should be to develop collaborative relations between staff and family in ways that facilitate a productive partnership in care decision making.

The studies highlighted the importance of information, communication, and relationships between families and staff. Staff-family relationships and communication were affected by a range of factors including staff attitudes and behaviours, extent and quality of staff-family

interaction, contextual factors such as the NH environment, and cultural factors. Some communication difficulties can lead to frustration and uncertainty and can affect decision making by family proxies[16, 21]. Communication could be improved through more regular contact – both formal and informal – between staff (at all levels) and family members, as well as through more explicit discussions regarding what information can and will be shared with family (e.g., regarding medical events, directions for care as the resident's condition deteriorates/changes), and by whom. The aforementioned case conferences could be established to provide a venue for staff, family and relevant care providers and support persons (i.e. GPs, chaplains, etc.) to engage in regular formal reviews of the resident's current situation, identify care challenges and to engage family directly in care planning and decision making. With improved communication that is open and values and acknowledges the input of family members (e.g. through spontaneous conversations and more structured follow-up meetings) a culture of more open and reciprocal information exchange can be developed. Central to such a cultural shift would be opportunities for family members to raise issues and disagree with staff in ways that are non-threatening to both parties and in which repercussions of such open discussion are not a source of stress. The information the literature provides regarding challenges to collaborative relationships and the characteristics of different relationships that affect family involvement or authority, such as Ward-Griffin et al.'s[25] typology, and the factors that impact the building of trustful, ongoing relationships[19, 21, 23], could be used to inform staff education and training regarding communication and interface with family members.

Two questions concerned the impact of collaborative decision making processes on family members, and the person with dementia. The second of these was not directly addressed by the qualitative papers. Although one study indicated that participation in decision making has

benefits for caregivers[20], the majority of outcomes or consequences reported related to the emotional impact on family. Decision making can be a positive but also stressful, challenging, and emotionally strained task.

One question concerned the strategies family surrogates use in decision making. The findings focused more generally on what information and other factors that influence family decision making. The studies presented multiple factors that families consider, including explicit and implicit wishes of the person with dementia, other values including their own, short and long term consequences and benefits of decisions, and the context of the illness such as indicators of health and quality of life. The surrogates in these studies had variable knowledge about the wishes of their relative, from a range of sources, not all of which were explicit or direct. Decisions sometimes needed to be made without full and clear information, full knowledge of their relative's wishes, or conflicting perceptions and preferences. These findings reflect the debate in the literature about family members' ability to identify correctly the wishes of the person receiving care[13, 14] and findings of studies which highlighted the low levels of formal directives and reliance on informal processes[31]. Even when the wishes of the person with dementia were explicit, they guided decisions to differing degrees. This finding is interesting in light of evidence that family members see themselves as advocates for their relative[11, 12, 13]. While keeping this in mind, family decision making could be assisted by increasing the support and information provided by staff to family members. Should family wish, this could be implemented through on-going discussion about their relative's condition, illness, and more detailed explanation of the dying process. Frequent in-depth discussions with family members about the family's values, cultural perspectives regarding death, and so forth, would assist staff to take these perspectives into consideration in care provision. In a time- and resource-

constrained care environment, other avenues for information-sharing could also be explored and implemented (e.g., online resources).

Limitations of the review

This review focused on family decision making for people with dementia in residential care. Therefore it excluded evidence from community settings. Such studies may provide additional information including about decisions that are more likely to occur in the community setting. This review was also restricted to papers in English. Some foreign language studies were identified during the search which might alter the findings.

Conclusion

It is clear that family involvement in decision making for people with dementia in residential care is challenging. A number of practice implications can be identified. Surrogates value their role in decision making and mostly want to maintain this role in the residential setting, although their preferred involvement varies. Family decision makers, whether formally or informally designated, should be identified and their preferred level of involvement ascertained by staff. Involvement should then be discussed and negotiated by staff and family.

Time spent with staff, particularly physicians, and discussions with staff are important for families to participate successfully in decision making. Effective communication is crucial, and needs to be developed and supported. Regular opportunities (both formal and informal) for information sharing should be provided as a matter of course in care provision, with the frequency and regularity of contact negotiated between staff and families. Supplementary information to support decision making, such as information about illnesses and their trajectories, treatment options and prognosis, and advance care planning and advance directives should be provided as the need arises, as this information is important in decision making.

Attention to effective communication processes is warranted, as it is clear that ambiguous communication and relationships are detrimental to family members' ability to participate effectively.

Decision making can be stressful and emotionally challenging for family, who face difficult decisions and can experience uncertainty and guilt. Support for caregivers in this role is important. Staff play an important role for families and relationships with them are a vital part of the family experience of care. Regular contact between staff and families would contribute to greater support for these family decision makers, and support and information for staff regarding how to best support family members would assist them.

Surrogates use a range of information from various sources in decision making. Knowledge of their own and their relative's life story, values, and wishes, and the information they receive about the illness, treatment options, and their relative's quality of life affect decisions. Adequate opportunities for sharing this information by all concerned parties need to be provided and supported. This may be supported by more regular scheduled contact between family decision makers and staff, as well as thorough admission processes which allow for discussion of care plans and wishes.

Notably, the majority of papers in this review addressed treatment and medical decisions. Decisions such as relating to the psychosocial, spiritual, and emotional domains of care were rarely identified in the studies. Further exploration of the various decisions in which family are, or could be, involved in the residential setting, would assist in building understanding of surrogate decision making. The variation in surrogates' knowledge and use of knowledge about the values and wishes of their relative also highlights an area for further exploration. Investigation of how the wishes of the person with dementia are weighed in decision making, in

what ways they do and do not influence decisions, and why family caregivers may or may not make decisions in keeping with these wishes would be of interest.

Family involvement in decision making is therefore challenging, and requires additional attention in both research and practice. In particular, the interactions and communication with staff and support available for families, and the roles of different stakeholders in decisions should be addressed.

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Table 1. Literature search strategy

Databases searched: CINAHL, Medline, PsycInfo, ISI Web of Science, PubMed, Embase, APAIS-Health, Ebsco Health Source, Sociological Abstracts, Proquest Digital Dissertations, PsycArticles, Proquest academic research library, Google Scholar, Mednar, Caresearch;
Setting: residential facility OR residential care OR nursing home OR aged care home OR long term care OR home for the aged OR residential aged care OR elderly care OR aged care facility OR care home;
Population: elderly OR frail elderly OR aged OR older adult OR older person OR older people OR care resident* OR resident* OR elder*; dementia OR alzheimer* OR dement* OR alzheimer* disease OR cognitive impairment OR diminished capacity OR dementia, multi-infarct OR dementia, vascular OR impaired capacity OR Creutzfeldt–Jakob Syndrome OR Lewy Body Disease OR Wernicke* OR Korsakoff* OR Huntington* OR Progressive Supranuclear Palsy OR Pick's Disease OR Binswanger*; family OR proxy OR family proxy OR spous* OR child OR daughter OR son OR relative OR partner OR surrogate;
Phenomena of interest: decision* OR decision-making OR plan* OR advance care planning OR advance care plan OR advance health directive OR advance directive OR care plan OR collaborative decision making; involve* OR engage* OR participat* OR collaborat* OR includ* OR inclus*.
Methodology: qualitative OR qualitative studies OR content analysis OR thematic analysis OR field studies OR multi method studies OR mixed method OR observation* OR experience OR grounded theory OR observ* OR focus group* OR narrative OR action research OR discourse OR phenomenolog* OR ethnograph* OR hermeneutic* OR lived experience OR life experience* OR interpretive synthesis OR interpretive OR interview* OR ethnonursing research OR ethno-nursing research OR ethnological research OR feminist critique, qualitative OR qualitative studies OR content analysis OR thematic analysis OR field studies OR multi method studies OR mixed method OR observation* OR experience OR grounded theory OR observ* OR focus group* OR narrative OR action research OR discourse OR phenomenolog* OR ethangraph* OR hermeneutic* OR lived experience OR life experience* OR interpretive synthesis OR interpretive OR interview* OR ethannursing research OR ethan-nursing research OR ethanlogical research OR feminist critique, qualitative OR qualitative studies OR content analysis OR thematic analysis OR field studies OR multi

method studies OR mixed method OR observation* OR experience OR grounded theory OR observ* OR focus group* OR narrative OR action research OR discourse OR phenomenolog* OR ethosgraph* OR hermeneutic* OR lived experience OR life experience* OR interpretive synthesis OR interpretive OR interview* OR ethosnursing research OR ethos-nursing research OR ethoslogical research OR feminist critique

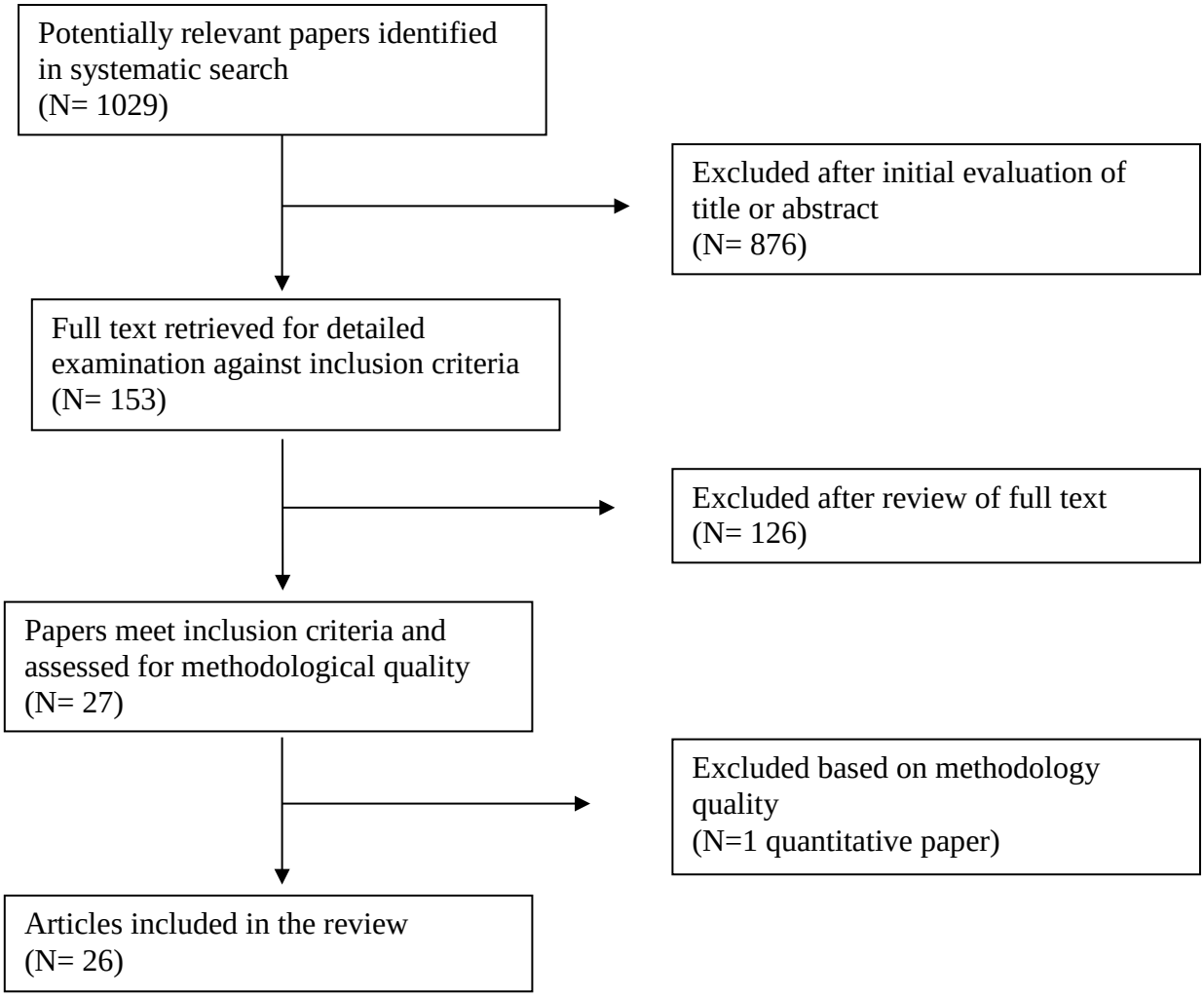


Figure 1: Selection of studies

Table 2. Included Qualitative Studies

Study	Methodology/ methods	Participants	Phenomena of interest
Black, Fogarty, Phillips, Finucane, Loreck, Baker, Blass & Rabins, 2009	Qualitative descriptive 34 semi- structured interviews	34 surrogate decision makers: Gender - 79% female; Ethnic background - 76% White, Age mean 61 (range 37 to 79), Education - mean years 15 (range 12 to 20), Relationship to Person with dementia - 38% child, 35% spouse, 27% other (sister (1), sister-in-law (1), friend (3), public guardian (3))	• How surrogate decision makers for nursing home patients with advanced dementia developed their understanding of patients' treatment preferences • What those preferences were • How confidently the surrogates held their beliefs about patients' wishes for EOL care
Caron, Griffith & Arcand, 2005a	Grounded theory 24 interviews	24 family caregivers of people with advanced dementia: Gender - Women (71%); Men (29%), Age - 40 – 49 (21%); 50 – 59 (42%); 60 – 69 (16%); 70 or over (21%), Relationship - Spouse (16%); Child (58%); Other (daughter-in-law, niece) (25%) 20 people with advanced dementia (not participants): Gender - Women (75%); Men (25%), Age – 60 -79 (5%); 70 – 79 (25%); 80 – 89 (40%); 90 or over (30%), Length of illness - < 5 years (20%); 5 – 10 years (55%); > 10 years (25%), Length of stay- < 5 years (60%); 5 – 10 years (25%); > 10 years (15%).	• The meaning attributed by family caregivers to the end-of-life experience of a loved one with dementia, care decisions for loved ones and, the actions of family caregivers with regard to this decision-making process
Caron, Griffith	Grounded theory	24 family caregivers of people with advanced	• The experience of family caregivers in

& Arcand, 2005b	24 Interviews	dementia: Age range early 40s – 83 years; Gender - 17 women, 7 men; Relationship - 4 spouses (3 wives, 1 husband), 5 sons, 3 daughters -in-law, 1 widowed daughter-in-law, 8 daughters, 2 nieces, 1 grandson. 20 People with advanced dementia (not participants): Gender - 15 women, 5 men; Age range - 63 – 94 years; Length of dementia - 2 – 22 years	making end-of-life care decisions for people with advanced dementia
de Boer, Droes, Jonker, Eefsting & Hertogh, 2011	Grounded theory 19 Interviews	11 Elderly care physicians 8 Relatives of people with dementia who had an advance care directive for euthanasia (no details)	• How advance directives for euthanasia affect resident care in Dutch nursing homes.
Elliott, Gessert & Peden-McAlpine, 2009	Thematic analysis 8 Focus groups	39 family members of people living in nursing homes with dementia (Gender - 82 % female; mean age 62; Religiosity - 38% actively religious; Relationship - 79% child)	• The ethical thinking used in end-of-life decision-making by family surrogates on behalf of their cognitively impaired elders
Forbes, Bern-Klug & Gessert, 2000	Naturalistic inquiry 4 focus group discussions	28 family members of residents with moderately severe to very severe dementia. Family characteristics: Relationship - 10 daughters, 4 wives, 4 husbands, 3 daughters-in-law, 2 sons, 2 sisters, 1 nephew, 1 sister-in-law, 1 grandson, Age range - 41 – 85 (M = 66), Gender - 20 female, 8 male. Resident characteristics: Age range - 75–95	• Families' decision-making processes (both cognitive and affective) regarding end-of-life treatments for nursing home residents with moderately severe to very severe dementia

		(M=84), Length of time since lost decision-making capacity - 2–9 years (M = 4), one outlier of 26 years, Length of stay - 4 months – 6 years (M = 2.8)	
Gessert, Elliott & Peden-McAlpine, 2006	Qualitative 8 focus groups	38 family members of nursing home residents with severe cognitive impairment. Family: Gender - 84% female; Age mean = 62; Relationship - 79% child and their spouse; 78% Active in religion; Race - 97% white. Resident characteristics: Gender - 74% female; Age - mean 88; Length of stay - 3.8 years	• The goals, beliefs, and values used by family members in making decisions on behalf of cognitively impaired, institutionalised elders near the end of life; • Commonalities and differences between the values invoked by families in rural and urban counties
Givens, Kiely, Carey & Mitchell, 2012	Grounded theory 16 semi- structured interviews	16 family members of people with advanced dementia: Gender - 63% women; Race - 94% white; Relationship status - 94% children of people with dementia; Mean age 62	• Sources of stress among family members of nursing home patients with advanced dementia
Helton, van der Steen, Daaleman, Gamble & Ribbe, 2006	Qualitative 24 semi- structured interviews	American Physicians, n = 12: Training - 8 family medicine, 4 internal medicine, 6 additional training in geriatrics; Mean age = 46 years (range 35 to 57); Gender - 4 women, 8 men. Dutch Physicians, n = 12: Training - nursing home medicine; Mean age - 44 years (range 33 to 60 years); Gender - 5 women, 7 men	• What factors do Dutch and US physicians perceive as important in their treatment decisions regarding nursing home patients with dementia who become acutely ill with pneumonia
Hertzberg & Ekman, 2000	Qualitative Non- participant	3 Group leaders: Gender - 2 female, 1 male; Age range 40 – 45; Training - Psychologists with	• Obstacles to a well-functioning relationship between relatives and staff in order to

	observation of three discussion groups (not focus groups) who met six times over three months (27 hours observation time)	experience working with people with dementia. 10 Relatives: Gender - 9 female, 1 male; Age range 45 – 80; 1 head nurse, 1 nurse aide. 3 Representatives from Dementia Association: Gender - 3 females; Age range 45 – 70; Training - 1 welfare officer, 1 head nurse. 9 Staff members (nurse aide/staff nurse): Gender - 9 females; Age range - 30 – 50	suggest promoters of a well-functioning relationship
Legault & Ducharme, 2009	Grounded theory 14 In-depth interviews	14 Daughter carers of institutionalised parent with dementia: Age range 44 -65 (M = 55.2 years); Marital status - 8 Married, 3 De Facto Spouse, 2 Single, 1 Divorced. Parents' age range (years): 71 – 91; Mean length of stay = 23.5 months	• How the role of surrogate advocacy evolves following the institutionalisation of a parent with dementia
Lopez, Amella, Mitchell & Strumpf, 2010	Qualitative descriptive 11 semi- structured interviews	11 licensed nurses: Mean age = 44.4 years; Race - 10 white, 1 African American; Religion - 10 Protestant, 1 Catholic; Training - 5 Registered nurses, 6 Licensed practical nurses (ENs); Experience - 21.3 years (mean)	• Nursing beliefs, knowledge and roles in feeding decisions for nursing home residents with advanced dementia
Robinson, 2000	Phenomenological 12 individual interviews	12 wives of patients with Alzheimer's: Age range 51 – 79; Religion - 7 Catholic, 2 Congregationalist, 2 Episcopalian, 1 None; Education - 5 High school, 4 College, 2 Post high school training, 1 No answer; Employment status - 9 retired, 3 employed.	• Surrogate decision makers' experiences of living through the implementation of the treatment decisions they made for their loved ones who suffered from advanced Alzheimer's when medical crises occurred.

		Men with advanced DAT: Age range - 58 – 81, Level of care - Most at level 3 (DNR order, not transferred to an acute-care unit for life-threatening illnesses)	
Siegrist, 2008	Hermeneutic 7 Individual interviews	7 family caregivers of people with dementia: Relationship - 2 husbands, 2 wives, 1 son (plus 1 daughter in law), 2 daughters	• Feelings and concerns of caregivers who previously cared at home and then admitted family member into a nursing home
The, Pasman, Onwuteaka-Philipsen & Ribbe, 2002	Ethnographic Observation in two nursing homes	35 Patients: Gender - 28 women, Age range 61 – 98 years old. 8 Doctors: Gender: 5 male, 3 female	• Decision making process behind withholding artificial administration of fluids and food (key factors in the decision making process, trajectories for the illness, advanced planning of care, and presumed wishes of the patient)
Ward-Griffin, Bol, Hay & Dashnay, 2003	Critical ethnography 34 in-depth focused interviews	17 family-nurse dyads; Patient details: Time from admission - mean = 1.5 years (range 3 months to 5 years); Nurse details: Age mean =45 (range 31 - 56); Gender - 100% female; Country of birth - Canadian (71%); Marital status - married (41%); Education status - diploma in nursing (65%); Full-time employed (53%). Family details: Age mean =65 (range 46 to 79 years); Gender - women (82%); Country of birth - Canadian (82%); Marital status - married (82%); Education - high school diploma (53%); Relationship to resident - wife (71%)	• How do families and nurses describe their relationships? • What strategies are used by families and nurses in negotiating their care giving work? • What are the consequences of the negotiation process between families and nurses? • What factors influence this negotiation process?

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

		Yes	No	Unclear	Not Applicable
	1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
*	2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
*	3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
*	4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
*	5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
	6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
	7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
*	8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

***** denotes five key criteria as identified by the two reviewers

Figure 2. Appraisal instrument for methodological quality

Table 3. JBI levels of credibility of findings

Level of credibility	Criteria
Unequivocal (U)	Relates to evidence beyond reasonable doubt which may include findings that are matter of fact, directly reported/observed and not open to challenge
Credible (C)	Those that are, albeit interpretations, plausible in light of data and theoretical framework. They can be logically inferred from the data. Because the findings are interpretive they can be challenged
Unsupported (Un)	When neither 1 nor 2 apply and when most notably findings are not supported by the data

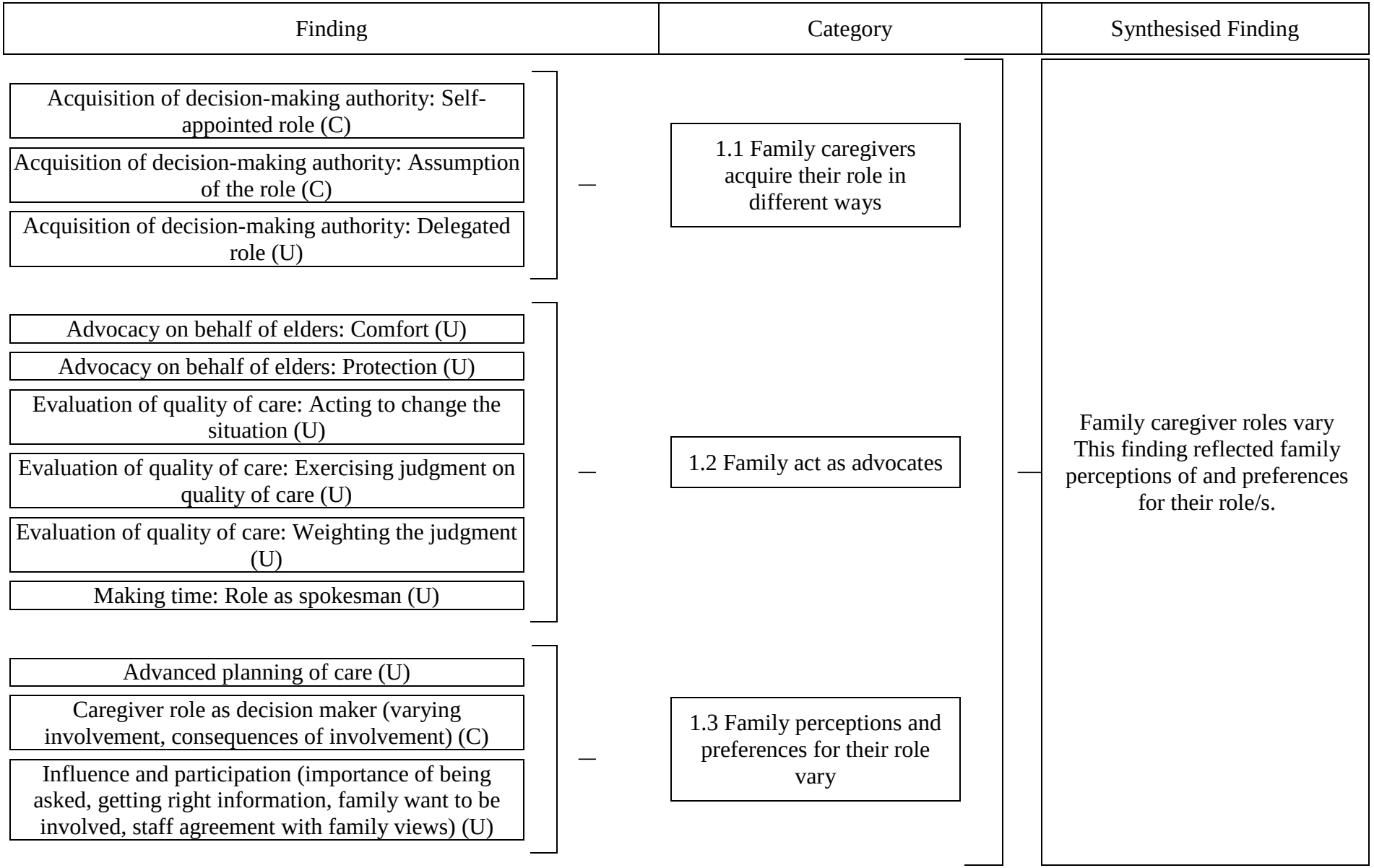
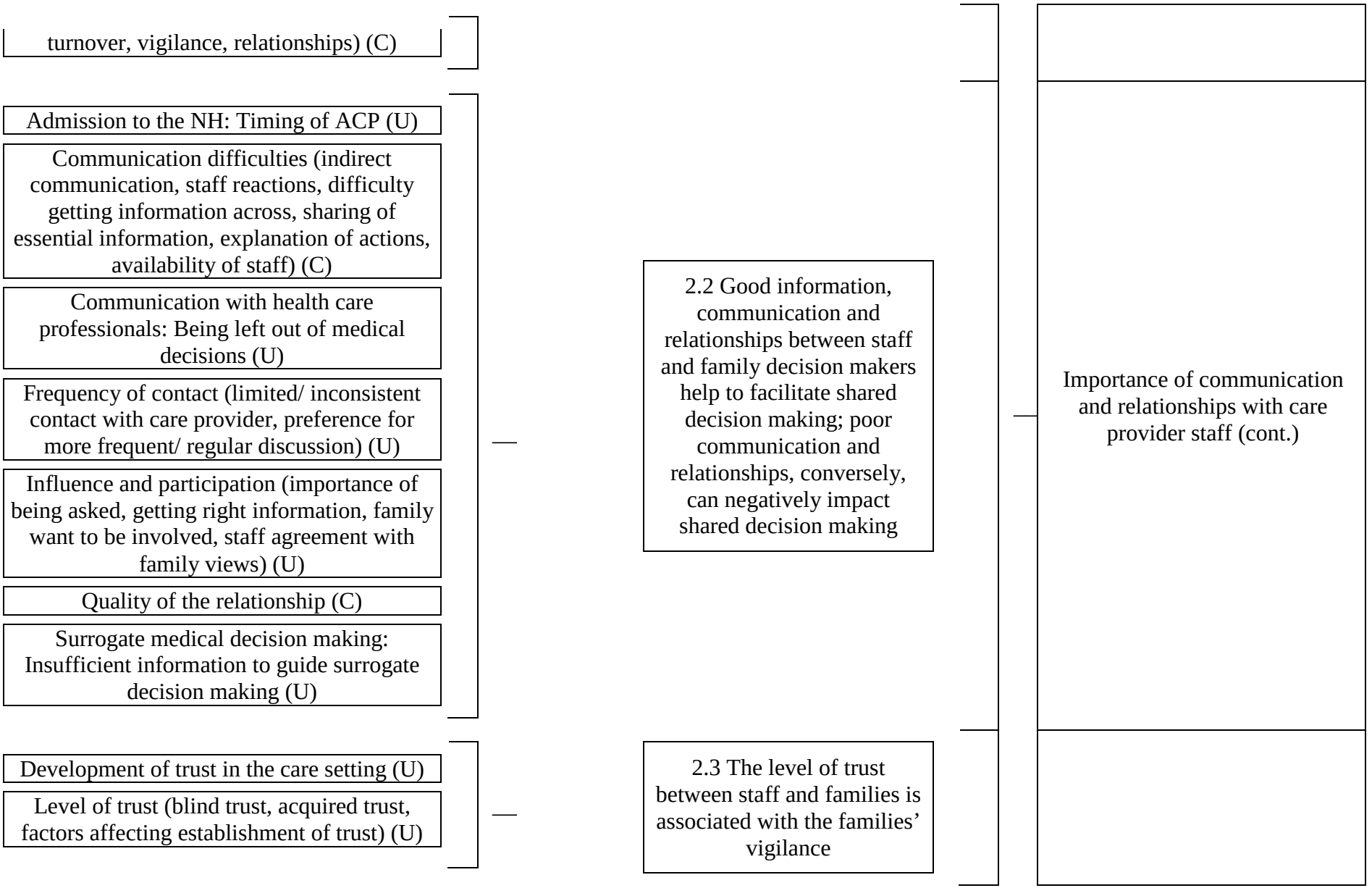


Figure 3. Synthesis 1

Finding	Category	Synthesised Finding
Ambiguous role in feeding decisions (C) Carative relationship (C) Collaborative relationship (U) Communication difficulties (indirect communication, staff reactions, difficulty getting information across, sharing of essential information, explanation of actions, availability of staff) (C) Competitive relationship (U) Conventional relationship (U) Family's patient care wishes (cultural differences) (U) Frequency of contact (limited/ inconsistent contact with care provider, preference for more frequent/ regular discussion) (U) Physician patient care role (relationships with patient/ family) (U) Process of physician treatment decision (relationships with family, cultural differences) (U) Uncertainty about moral agency (C) Uncertainty and distrust (difficulty obtaining information, lack of knowledge and staff	2.1 The relationships between staff and family, and the extent to which staff discuss with and involve family vary	Importance of communication and relationships with care provider staff This finding reflected the importance of information exchange, communication and relationships between families and staff.


turnover, vigilance, relationships) (C)
Admission to the NH: Timing of ACP (U)
Communication difficulties (indirect communication, staff reactions, difficulty getting information across, sharing of essential information, explanation of actions, availability of staff) (C)
Communication with health care professionals: Being left out of medical decisions (U)
Frequency of contact (limited/ inconsistent contact with care provider, preference for more frequent/ regular discussion) (U)
Influence and participation (importance of being asked, getting right information, family want to be involved, staff agreement with family views) (U)
Quality of the relationship (C)
Surrogate medical decision making: Insufficient information to guide surrogate decision making (U)
Development of trust in the care setting (U)
Level of trust (blind trust, acquired trust, factors affecting establishment of trust) (U)
2.2 Good information, communication and relationships between staff and family decision makers help to facilitate shared decision making; poor communication and relationships, conversely, can negatively impact shared decision making
2.3 The level of trust between staff and families is associated with the families' vigilance
Importance of communication and relationships with care provider staff (cont.)

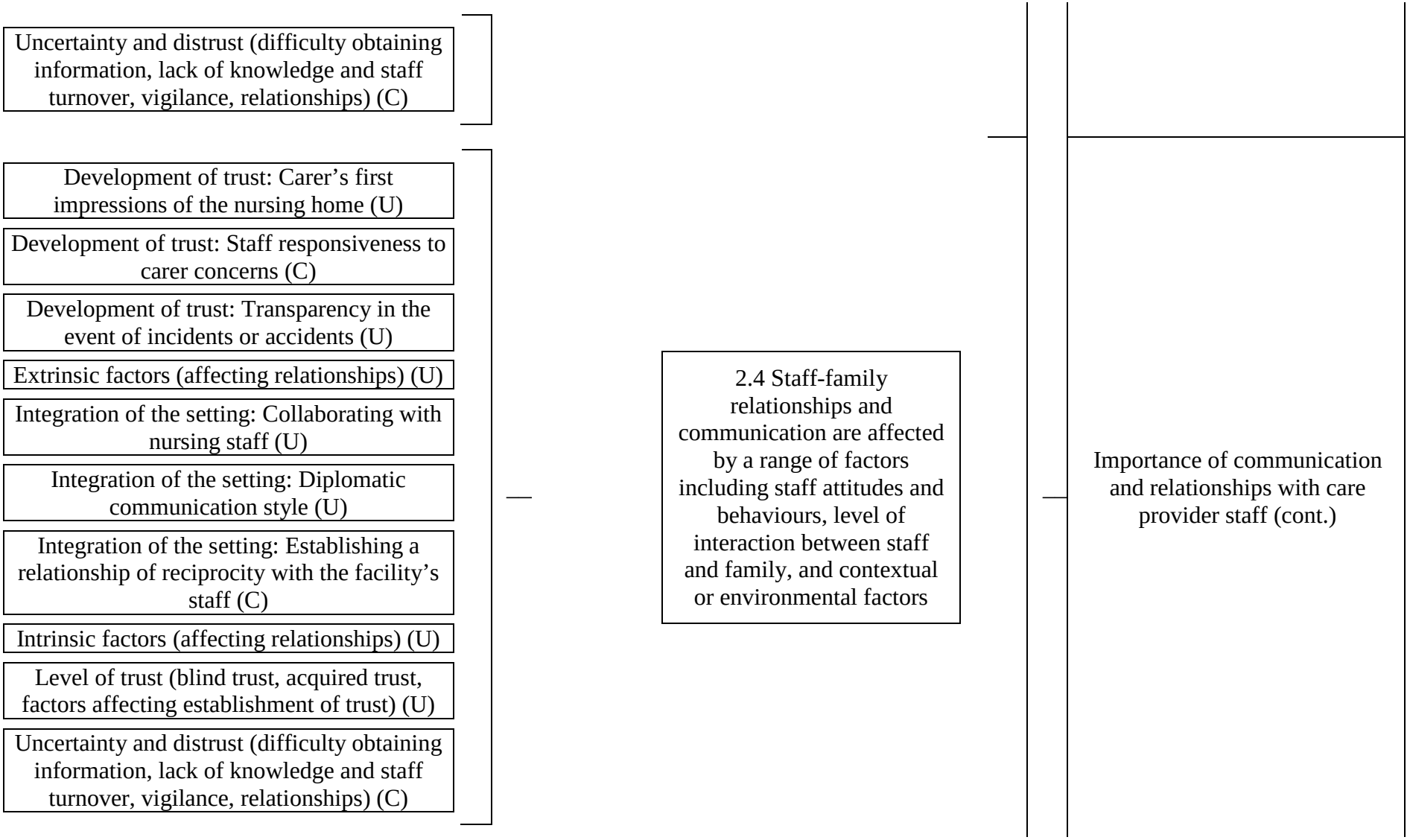
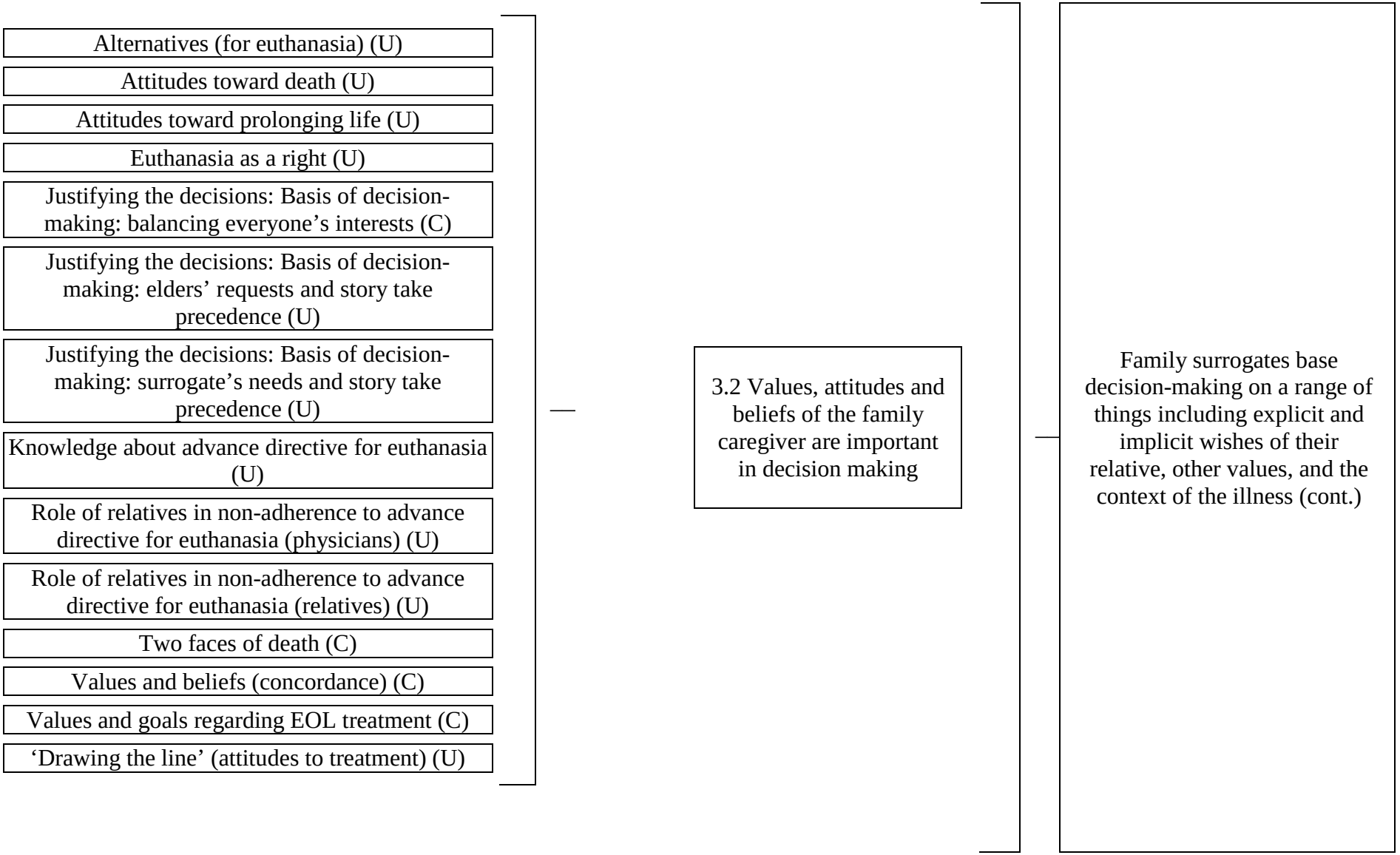


Figure 4. Synthesis 2

Finding	Category	Synthesised Finding
Discussion about advance directive for euthanasia (U) Influencing factors: Barriers to creating advance directives (C) Influencing factors: Barriers to having EOL care discussions (U) Influencing factors: Catalysts for discussing EOL care wishes (U) Sources of information: Discussions of EOL care wishes (U) Sources of information: Other ways of knowing EOL care wishes (various sources) (U) Sources of information: Surrogates' reports of advance care directives (C) Sources of information: Advance care directives in medical records (agreement between surrogates' reports and the chart reviews). (C) Understanding of patients' prior wishes: Surrogates' confidence in knowing patients' prior wishes. (C) Understanding of patients' prior wishes: 3.1 Specificity of wishes (U)	3.1 Family decision makers have variable knowledge about the wishes of their relative	Family surrogates base decision-making on a range of things including explicit and implicit wishes of their relative, other values, and the context of the illness This finding reflected the broad range of factors on which families base their decisions.


Alternatives (for euthanasia) (U)
Attitudes toward death (U)
Attitudes toward prolonging life (U)
Euthanasia as a right (U)
Justifying the decisions: Basis of decision-making: balancing everyone's interests (C)
Justifying the decisions: Basis of decision-making: elders' requests and story take precedence (U)
Justifying the decisions: Basis of decision-making: surrogate's needs and story take precedence (U)
Knowledge about advance directive for euthanasia (U)
Role of relatives in non-adherence to advance directive for euthanasia (physicians) (U)
Role of relatives in non-adherence to advance directive for euthanasia (relatives) (U)
Two faces of death (C)
Values and beliefs (concordance) (C)
Values and goals regarding EOL treatment (C)
'Drawing the line' (attitudes to treatment) (U)
3.2 Values, attitudes and beliefs of the family caregiver are important in decision making
Family surrogates base decision-making on a range of things including explicit and implicit wishes of their relative, other values, and the context of the illness (cont.)

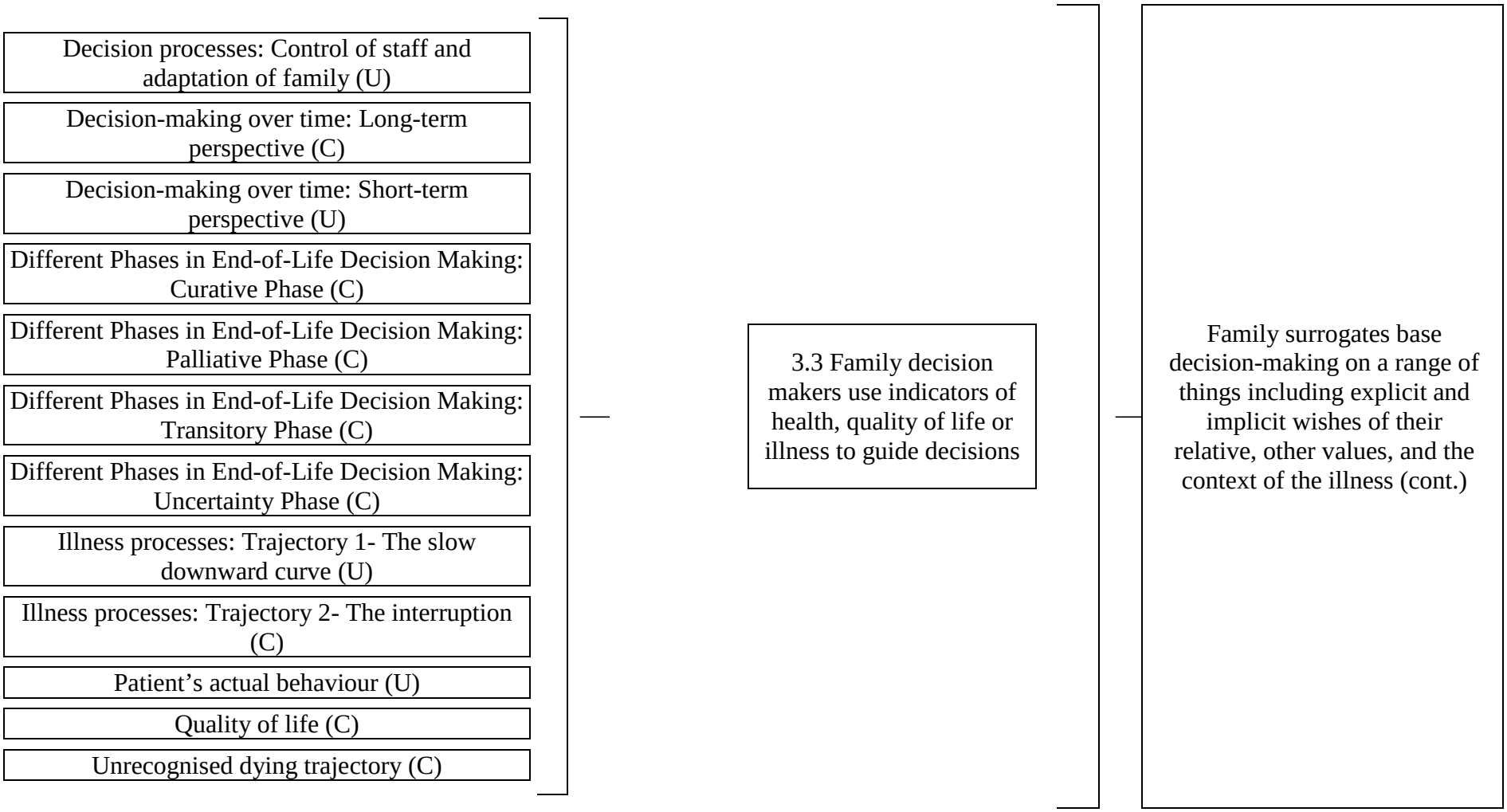


Figure 5. Synthesis 3

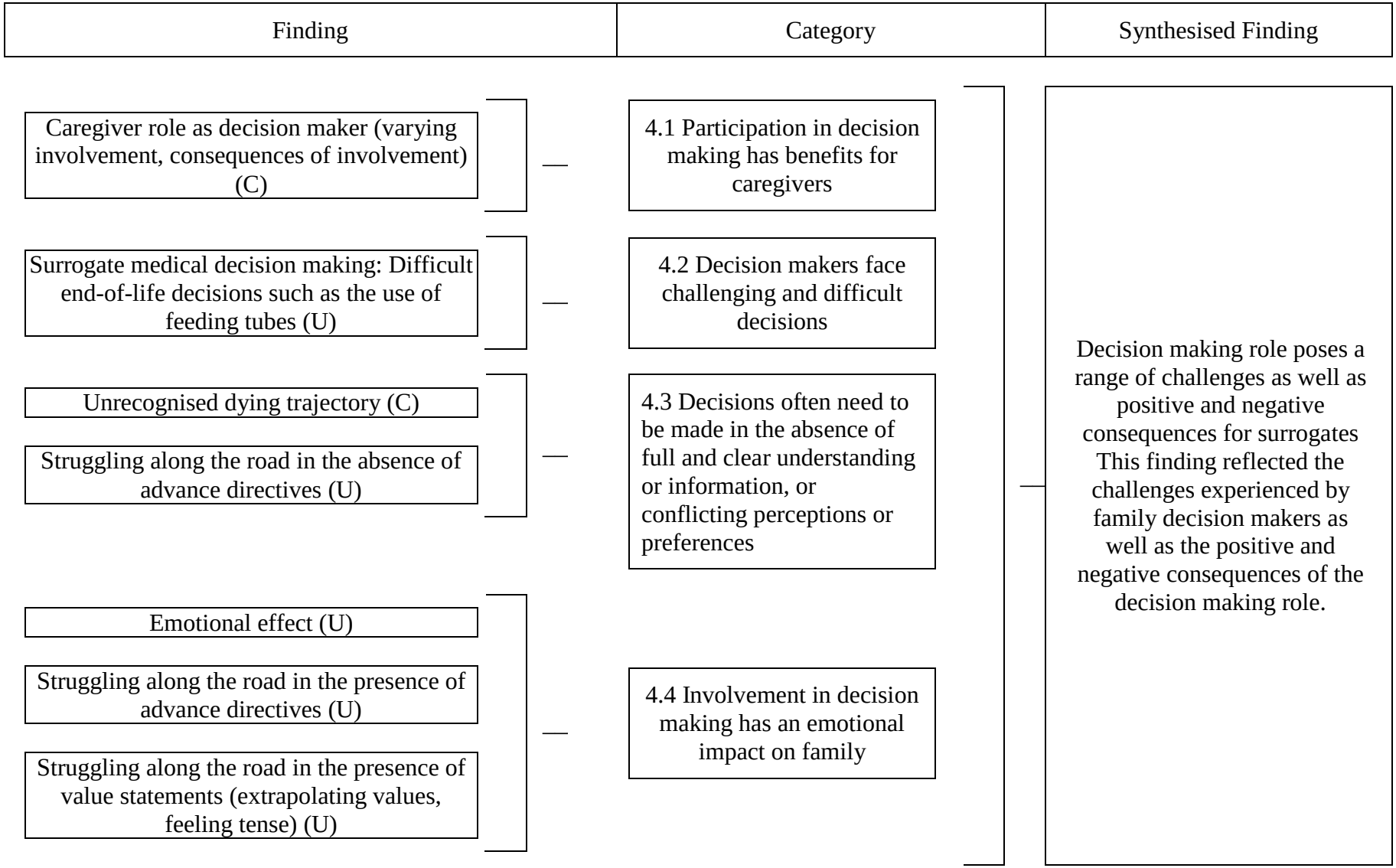


Figure 6. Synthesis 4